

## ORAL HISTORY RECORDING TRANSCRIPT

### 'Fighting for our Rights' project

<b>Surname</b>	Johnson
<b>Given name</b>	Jessica
<b>Date of birth</b>	1952
<b>Place of birth</b>	Surbiton, Surrey
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<b>Name of interviewer</b>	Jen Kavanagh
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Q: This is an oral history interview with Jessica Johnson by Jen Kavanagh on Tuesday 30<sup>th</sup> May 2017. The interview is taking place at Jessica's home in Surbiton as part of the Kingston Centre for Independent Living's Fighting For Our Rights project. So thank you very much for being interviewed today.

A: Thank you.

Q: Could we start with you stating your full name please?

A: Jessica Johnson.

Q: And what is your date of birth?

A: [REMOVED] 1952.

Q: And whereabouts were you born?

A: Surbiton Hospital [laughs].

Q: Ah, very local. What were your parents names?

A: Frederick Charles Chinnick and Dorothy Winifred Mary Chinnick.

Q: And what were their professions?

A: My father was a greengrocer manager for Gerard's locally, well, within the borough, Kingston and New Malden. And my mother had originally trained as a nanny and was then home with us as a family.

Q: And have you always lived in the borough?

A: For the majority of my life. I grew up in Elgar Avenue in Tolworth and then I was only away when I was nursing training, so I was Great Ormond Street, London, and Royal Berkshire, Reading. Then came back, was married in Tolworth to Wes, and then for the first, 1974, first ten years of our married life we lived just over the border in Ewell in Surrey, and then we moved back here in 1984 and have been here ever since in Surbiton. So the majority of my life has been in Tolworth and Surbiton.

Q: And whereabouts did you go to school?

A: Grand Avenue, Tolworth Primary, and at that point, so we're now talking 1960s, we had eleven plus where we could also go out of borough. So I then went to Roseberry Grammar School in Epsom having passed my eleven plus, out on the 418 from Elgar Avenue in Tolworth straight door delivery to Epsom and back again from there, so still very local borough, although out of borough grammar.

Q: And so what age were you when you finished school?

A: 18.

Q: And then you went on to study nursing?

A: Then I went to Great Ormond Street Hospital for sick children and did a combined general nursing, paediatric nursing, midwifery nursing, and came back, was married and then trained as a health visitor and worked in Epsom at that time.

Q: Okay, cool. And so how old were you when you met Wesley?

A: I was probably about 15 when I was first aware of Wes, because I had another boyfriend at the time. I was at Emmanuel Church, Tolworth, youth group, and Wes was at Christchurch Surbiton youth group, and the two churches used to meet and we both had big youth clubs really, and we used to meet for joint youth events and we used to meet for combined hockey matches on boxing day down on the Hogsmill by Elmbridge in Tolworth, and so that's when I was first aware of Wes, but I was 17 when we first really met, and I went to Wes for drum lessons. I came here for drum lessons. He had the drum kit but he'd had a motorbike accident by that time, he was unable to play the drum kit, and I came to the house that we're in now, which is where Wes was living, to Wes for drum lessons so that I could play at a youth service at Emmanuel Tolworth. So he lent me his drum kit and that was the start of getting to know Wes. So yes, I was sort of 16, 17-ish.

Q: And what was Wes' full name?

A: Michael Wesley Johnson, and he decided when he was about ten I think that he was going to be called Wes. His brother, he says, wound him up, his older brother at some point, so he decided he'd call himself Wesley and he's been really known as Wesley ever since, which meant we always confused the health service wherever we went because he was always called Wes. And then when people would call him Michael he'd get very cross [both laugh].

Q: And what was his date of birth?

A: He was 2<sup>nd</sup> July 1945.

Q: And was he born locally as well?

A: Surbiton Hospital, so we have that in common as well [laughs].

Q: Would you mind explaining what happened in terms of Wes' accident, what caused his disability?

A: Yeah, so Wes again grew up in the borough here, and he would go to work from Surbiton to Brentford, which is where he worked, on a motorbike, and he had a new motorbike for his 21<sup>st</sup> birthday and he was driving through Kingston and along what is now the Canbury Park Gardens way, and a car came in the opposite direction and hit him, and he came off his motorbike, hit a bollard by the Thames, the bike went into the Thames and he broke his back and pulled his shoulder from there. So went very quickly, well from Kingston then to Stoke Mandeville straight away. So that was just a few weeks after his 21<sup>st</sup> birthday.

Q: And what treatment was he then receiving once he was at Stoke Mandeville?

A: So he was there--, I mean I didn't know him at that stage because he's seven years older than me. So as I say, I was 17, I met him when he was 24 so although I knew of him, if you like, around--, so he was in Stoke Mandeville for sort of nine to ten months straight the way through, and initially he had what they call a T3, T4 lesion of his spine so he had no movement from sort of lower chest down, obviously doubly incontinent. But he also pulled a brachial plexus lesion in his left shoulder, so his left arm never had full momentum really. And so he stayed in Stoke Mandeville, he still remembers the names of the matrons, as he called them, and the sisters that bullied them into actually doing as much as they could for themselves. But he did say he was, at that time he was at what was then Kingston College of Technology doing electronic engineering and he'd already met somebody on his course in a wheelchair. So he said it wasn't the paraplegia that threw him so much, it was the missing of his left arm because he was by that time getting to be a really accomplished church organist. So he was aware he could use two arms but it was the thought of having only one hand that was his real problem I think from there. But he spent, as I say, nine to ten months in Stoke Mandeville. He then came back to 23 the Crest where we are now, to his parents home, and they put a bed downstairs. But then they also managed this annex put on the back of the house here, so the single room here. His uncle was an architect and had been designing this house anyway about ten years before, so they added on a room at the back to a house they had already had previously built as a family before his accident, but built that on. And so he then had a room downstairs and then varying bits of equipment coming from Kingston then. Some Kingston Authority, some sort of put in with the building of the room and things a little bit, but I mean this was still very early days for adaption because we're talking here 45, 65, 1968, so early 1960s, late 1960s.

Q: Do you know what other services were offered to him and his family at that time?

A: At that point I think his mother was around [laughs]--, they seemed to have, well he had a superb GP, and I think Dr Roberts in Surbiton here was, again became a very honest, as I said, he seemed very young but very honest and got to know the family well, so, and got to know Wes very well. So the main things were the GP. From Stoke Mandeville they taught Wes as far as he could to work on what you call an automatic bowel system, so through use of Senokot tablets and suppositories, with help every three days he would go on the toilet in the evening, taking the medication. And so it was family really that did that, so his mum and dad. And over the road they had, literally, somebody else who was a nurse, and so the first few weeks she seemed to help rather than services outside, they seemed to sort of be far more independent. So I mean by the time I knew Wes here, his mum and dad helped him with the toileting from there. He had a urinary drainage bag and everything through, which he did and things himself, and then his mum worked just a few days and there was another neighbour at the bottom of the garden, a retired couple, and they used to drop in. So if Wes was in bed sometimes they would help him backwards and forwards as well. So it seemed very much it was community support rather than support from outside really for that time. So I never, no, I mean while I was sort of going out with Wes and before we were married, I never really saw anybody else, neither did I really see him going into hospital. So it was really sort of community care. He'd, by that time he'd started to go back to work. He worked as an electronics engineer in Brentford, so again, well, no, to start with he did a few days in Tolworth Tower where his mum worked, he got a few days just office stuff, so he worked his way back in very gradually to things. And then, well of course I say that, the next real big help was the blue [Invacare? – 10:36], so it's actually, once he--, he loved driving anyway and once he got one of these, initially it was the little electric wheelchairs that went about 20 to 30 miles an hour, but that was his life changer, as he said. Because once he had that then he would be put in the car, helped into the car at this end, and he went back to the firm that he was

working with in Brentford, they moved stuff downstairs for him. And he was also at Kings College of Technology and they moved his classes downstairs for him to finish his HND. So bit by bit, I mean I'm talking over sort of three years, two, three years really, gradually, he got back to doing electronics engineering, soldering with his mouth, I often wonder if he took in a bit too much, but he could manage a soldering iron with his mouth really and one hand and everything else, and so was on the small printed circuit boards, and stayed working there and built his way up from going sort of two to three days a week to by the time we were married, so when I was 21 and he was sort of 28-ish, by the time we got married, he was going every day. And I mean he would leave home then, I'd have to get him up about six, he'd be leaving home at seven to get there for eight and he would work his way through until sort of six-ish and come home for seven-ish. So he got himself back up and working with help from me by that time then, and from work at the other end. So he was never afraid to ask for help from people that were around.

Q: Yeah, how did--, so once he was back home after being at St Mandeville, how did your relationship develop?

A: Well because he was out with the youth group, and so as I say, I came here for drum lessons, and I was still at school doing A' Levels and I was doing A' Level English, maths, music, and he would come round in his little blue Invacar after work and park outside my house in Elgar, and I'd go and sit out there and he'd do my revision with me [laughs]. And then I mean if we went to a concert, which was the first thing we did, which was actually at Surbiton Assembly Rooms, and it was a sort of light musical thing, and his mother then had to be the chauffeur, so his mother would drive and help him in and out of the car, and then she was very good at sort of taking a little bit of a back seat. So for a while she was the chauffeur, so we went to things like that. The youth group things, he then started to come to some of the youth group things that I was at as well, and then--, actually when I was 18 really, as I finished school, was my first holiday by flight. His family went to Jersey, which they'd done before, flew out there, and I flew out to join them, that was my first flight. So I was out there with his family then so I would go on sort of family holidays with them. So it was very much then, Wes was sort of--, they were doing the care, I never did the care until a bit later on, but it was his mum and dad really that did the care for him there and managed, I mean again, he could park, he could have a wheelchair that had the sort of right and left drive on one hand and then, when did he first get--, probably when I was about 20. It was before we were married, he moved, had a small Mini Clubman converted to drive just hand control, well one hand, and an accelerator brake, which his left hand could do, which we still have a car converted to that way then. So that was before mobility, before anything health sort of came in. But that was done on, he had compensation from his accident, so that was sort of done under that really. So for a while he had that, that we could go out in together as well as the blue Invacar, which was meant to be one drive only but I admit I could squeeze in, I was quite small, I could squeeze in and travelled around in the blue Invacar. And one of our biggest queries a lot later on was when we had a son who one Christmas eve went out helping dad deliver the Christmas cards, hidden in a blue Invacar. I was at home and then I got a little knock on the door to find a police officer with my son in the car saying, "I saw two heads in this blue Invacar that shouldn't have been there so I've brought this one home!" [Both laugh] So you know, "It's Christmas eve, we'll let it go this time but don't let it happen again," sort of thing [both laugh]. So I mean we used to, yeah, just make the most of things really. But with the use of the blue Invacar then the Mini Clubman converted, which I then learnt to drive on later as an automatic, but otherwise he did the bulk of the driving, and I was the loader of the wheelchairs into everywhere and manager of all the care equipment. And sort of by that time I learnt again to do all the care, so I did all the helping on the toilet, all the wee bags, I've been known to flush bits of the wee connections down the toilet, which was on our honeymoon so we had to come back fairly quickly to get another spare [laughs]. And those sorts--, so you had, I was thinking today, he's a fixer. He was somebody with engineering mentality, so if the chair couldn't get into somewhere we ended up carrying planks of wood round with us of varying sizes that you could somehow get us from A to B over steps. He wasn't afraid to be lifted up flights of stairs and things by friends and those sorts of things, so, and we had a really good group of friends, I think that was the other thing. So we had friends, some of whom knew him before his accident that stayed with it that have been very loyal, and so always have sort of helped us out really so we weren't isolated. So we just got on with living in Surbiton really [laughs].

Q: What year did you get married?

A: 1974.

Q: And what was the living situation for you both after that?

A: What we did again, really using the claim money from the accident, there was a bungalow just over in Riverview Road in Ewell, so we went into that bungalow, three bedroom bungalow. Then of course we went from being Kingston here to Surrey, so Surrey there did ramps and they did a hoist for us for the bed. We found this Clos-o-mat toilet, which was quite an experience, which is where you've got the, acts like a little douche, a shower thing as well and a hot water boiler, which sort of worked, but it meant, because we had to have the toilet that was there taken out and this one put in, so there were no things like matching--, you couldn't match anything or anything now, you had to fit whatever went in. And then you had to get--, in fact we didn't have a hoist in there really, we used to do a transfer, he and I used to work a transfer then on to that toilet and off. So we had a ramp to the front door, we had a Clos-o-mat toilet and we had a sort of monkey pole adaption for over the bed really so that he could hang on and then I'd always transfer him from chair to bed and bed to chair. So that was that and the toilet, otherwise it was flat-ish outside. So we were there from 1974, Stephen, son was born there, and then we moved here, back here to what was the family home, which had already had the initial conversions done in 1984. But then that meant, his parents had been here, for a while they did a swap, they went to our bungalow and they were down sizing really to live with Wes' sister. So they moved into that bungalow for a while, we came here, but we then ended up having the through the ceiling lift, a full lift from ground floor to upstairs so that we could use upstairs for sleeping but we still used the old downstairs toilet, which got adapted a little bit, which already had a sort of ceiling hoist on it. So I say nothing's ever been fully purpose built, but we've sort of stuck things together rather than had anything that's fully done. 'Cause then it was Kingston that have put the ramps back in, so front and back garden ramps, otherwise we just had the monkey pole in the same way for the bed. And we managed, I suppose right through until things began to go a bit awry with urinary infections and waterworks were the main thing, at that point then there wasn't a urologist at Kingston Hospital so we got referred to Surrey County and had a really good urologist, Mr Notley down there, who told Wes the first time we went that, you know, "Your life expectancy, mate, can't be that good with these. The minute you've had the antibiotics for this, you know, once you're immune to these that's it, so you've got to keep your system working," and he would tell it straight. And he then really monitored us for a long time then and every time the wee infections started to come we always felt we'd got support from there and we would go down. We went through varying sort of, yeah, I mean things with prostate and bladder, as the bladder was filling up, so there were varying ops then under urology there. And our challenges then became that with Wes being paraplegic, often you'd go into the hospital but the hospital didn't have the facilities to really look after him for the pressure sore. So sometimes they'd do the ops and then it was better for him to come back home. Actually the other thing that I've forgotten, that both Kingston and Surrey, we had ripple mattresses on the beds, ripple beds, so that was always carrying, so we'd take it on holiday as well, but it was a ripple bed, which then would sort of run all night, which meant I didn't have to turn him in the middle of the night because it does make a noise and I remember that, but, 'cause the hospitals didn't always have those. So it was always safer then for Wes to come back home, so we sort of, we ran into some difficulties with that. The other challenge then were pressure sores and it was pressure sores either on sides or on ankles and feet, and then when he was in his fifties really it was circulation with feet was bad, and then we came back into Kingston Hospital for those. And then any of the pressure sores then, we got to know the community nurses quite well because they used to come in and they had varying stages of different types of dressings for pressure sores as the science sort of develops with them. And so at times they would come in and change those and work with those. And then along with that then because they were beginning to become slightly more frequent, we were then referred to the [clicks], what's the word I want? Ah, not physio, the, I want to say osteo, no, no, no, no, this is brain gone. Oh, I know it so well. People anyway that help with all the different cushions and the different wheelchairs because we were then thinking it was the wheelchairs and the cushions that were difficult. So we then tried out a whole lot of different ones, and whereas we'd always had a sort of, I was either doing the pushing or Wes would push with a wheel, we then moved to an electric wheelchair when he was in his late

fifties probably. And then that brings in more challenges because although in some ways they gave him sort of less problems, 'cause the other thing was his shoulder was actually wearing out by this time from doing all the pushing. So he was under St George's and knowing people then for that, and then they wondered if also he was getting pressure back on his neck and if it was a neurology thing because he was having difficulty moving his arm. So that's when he went then to the electric wheelchairs, push button, but that then meant actually we could get into fewer people's houses because they're bigger and bulkier, and even with our bits of wood we still couldn't do that. At the same time as that, again, was this late fifties for him, age-wise? The Invacar would take them out of action, and so that was a very hard time for him. I've still got the number plate in the garage of the last one, cried I think when that disappeared. But it then went on to mobility so we were one of the first people to have, it was then a Suzuki Wagon that was then converted to drive from wheelchair. So again, yeah, so he had the electric wheelchair by now and we had to go, the only garage that would do it under there was West Bromwich in Birmingham, so we had to go up to West Brom for measurements and testings and everything else. And it took, it probably took about four to five months for them to get it right. We had to be checked by the mobility people as well, tested out with everything there, and he came away driving the Suzuki Wagon from wheelchair. Now because we were some of the first to test these and they're all electronically controlled, the ramps and everything else, we've had our fair share of, particularly the electronics not working, so you could be out somewhere and the ramps would be stuck up or down or not let us in or not let us out or run out, all the controls would die down. Saying that, it gave again him a mobility with the Suzuki so that he could go. It fascinated all the children here who thought that Darth Vader was coming out of the car every time [laughs], so it caused its amusement. And so, you know, he carried on with that one through, but then it was beginning to get to the stage where they didn't have enough spare parts for that each time it broke down so we then went back up to West Brom and then had a Renault not under mobility this time, but just with a second hand Renault they did. Again, similar problems with ramps and varying things, and it was a heavier drive really in a way, so it was better in some ways, better passenger room for me but tougher in some other ways, so we had that until he died really. So we had the cars. By this time, as shoulders were wearing out and as pressure sores were increasing, also the urinary works weren't working quite so well, so although we were now under Kingston for shoulder and any neurology things that they were testing, and then he also had a very high red blood cell count so he was under Kingston Hospital for that, but stayed under Surrey county for the urology because it seemed to make sense because we'd always been there. And although Mr Notley retired we stayed with them. They then decided that because of what was happening to the bladder and it blowing up too much, that we would then have, were catheterised for a while. So I then spent probably two years doing catheterisation in morning and evening, which I mean in retrospect meant we had a certain amount of freedom because it didn't worry him too much in the day as to what was happening, but it did tie us all the time to doing it and I did it. But then still the bladder, infections were happening and the bladder still wasn't right, so he then had a whole, actually put in, an internal catheter put in for about the last 18 months, two years of his life really. And that took him a bit of getting used to, he used to be able to empty bags really anywhere and everywhere [laughs], you know, in trees or whatever. Suddenly you had to really, when it was higher up you had to try and find a toilet to get into that caused more challenges. We know where the toilets are that you couldn't get into, or you got into and they were full of boxes and stuff and you couldn't empty them, so all those things. And we have helped various people at church and in different places trying to get the right sizing and the right turning, but it's hard and they're still not right with those really. So in the end he was, it was a struggle, I mean I'm now aware just how much effort he put in to every day, but he was always ready to go really. I mean he was getting more tired by the end, but he had a big social, well, a social life, but I would say musical life in the end. And that was why he was really part of the community, so he, by the end, the last few years, he was playing brass band with Cobham brass band. Now that meant he could go in the car here, it would require people to help him at the other end with cornets and music stands and everything else, but he did all the band concerts and band displays with them. He played with them for about six years and won bandsman of the year one year, really because he was so determined and so reliable, in spite of all the urinary everything else. And his musicianship was such that he could always tell when the rhythm was out [laughs] or they were flat or not in tune, and he'd help the younger ones next to him, although he was only really just learning the cornet. He was a music teacher, although he'd never done it, he was a natural music teacher. So it was your brass band, he was tenor at Kingston choral society, really which was Surbiton oratorio

society originally, which he joined I think before his accident even, so he was there from sort of 18 right the way through until he died, so he always sang with them. He sang in a variety of church choirs, we were at St Mathews and he was a key part in the whole musical life there, both for the church choir but also playing cornet, writing music and other bits and pieces as well. Tiffin, son was at Tiffin, and Wes was a key part of the Tiffin oratorio singing that went on then every year after year. So again, right up until his last years he could be seen in the Tiffin oratorio choir. He'd go and help out the Kingston grammar school equivalent of the oratorio choir because he was a tenor, but he could also sing other parts, so he was quite well known. But he could only do that because people at the other end would always help him out if he needed it, whether it's with music or things falling out of his bag or dropping it or whatever. So he developed a whole band of supporters, just as he'd done at work, he did that with choir, with band. And the same, if you go round the local shops, the chemist, the post office, the postman here, he would be in conversation with him so they always felt they worked with him. So it was community care in the real sense of community from having a relationship with people as much as with paid staff. He became aware of KCIL and would trot down and he would talk to me particularly about Robert, Robert if you ever listen to this. And he was by the end very worried about Robert and Robert's parking because he didn't think Robert would get a parking place. And as the personal payments was coming in they were helping us to try and sort out care, because I, as a lecturer then had times when I would be away external examining. And so initially, I usually did the bulk of the care but if I wanted cover for a couple of nights, initially we had one company that we used and we got to know Jane who was the same person time after time and that was brilliant and she was brilliant. She got to know Wes, she could sort things out and she seemed to do everything on her own. Then gradually as health and safety and varying other aspects come in you couldn't have one person, you had to have two, and they tended to be two different people each time, and then Wes would spend each time trying to tell them what to do and sometimes the language didn't always get to the level of the understanding that it was wanted. So in fact almost the last time I went and I could tell something was wrong because Wes hadn't rung me to say goodnight or anything there, and I knew then he didn't want to do that because he didn't want me worried, and he really had had a tough time. It was a time when he'd wanted--, and to be fair on them all they were all trying, community nurses had to come out, that was when it was catheter changing. So they needed to come and do the catheter changes but they needed the carers to come and put them to bed. The nurses wouldn't put him to bed, that had to be the carer's role, so they had to come first then the nurses could do the catheterisation. Whereas in the morning the nurses had to be in first to do the catheterisation and then the carers pick him up. So it was asking for that joined up thinking, and that proved a huge challenge and again, it was just one of the things that began to cause high anxiety. So that's when we were going back and we were starting to be in discussions with KCIL about creating adverts for a personal--, so somebody that we could really get to know. And then really just a few weeks before he died, watch this, [become emotional] we had a visit from just an amazing social worker who we'd never seen before, and he just seemed to manage very respectfully to fully understand both of us. So he just referred us to, suggested, gave us the details for something, I think it's called Home Instead, it's another unit in New Malden, so we'd literally just had the first visit from them and were looking to see if we could, again it would require payment and balancing things out but we were sorting out allowances and things then, and we felt this was probably the best way forward if I did need, it was only just a few days periodically, that you know, we'd--, but the way they worked it is they would send people round so they would get to know us anyway before I needed that and we'd build up a relationship over time. So we were just having those conversations, but then we never needed to use them because Wes died suddenly and unexpectedly in the night, so it was the shock element in the end, which is still around a little bit from there. But I think we've lived through many changes really. We've always been very dependent on the NHS really, so it's all been NHS care, and the bulk of it has been excellent. There's areas, when we've had excellent care though then you do note that it is very different now when we don't have say one named GP. So by the end, in fact when Wes died, and I've been back to the surgery, nobody's clicked that I'm Wes' wife, and you know, those sorts of things. In fact nobody came up, because he died in the night nobody from the surgery came out. So you know, we haven't, there's that link, whereas the old GP would have been here with the tears and everything else as well. The same way, I mean we had core groups of community nurses and again there's the--, being able to build up a relationship made so much difference, for them I feel as well as us, and it's the job satisfaction then and the sharing and the caring, and that's when it worked well, and the same with the carers. And the same with, I mean all the wheelchair people,

the repair people, it's been very emotional for me actually having people coming in to collect things to take away. [Starts to cry] And there was one young guy with the wheelchair, I'll go and get--, who, I mean I'd left a message to say Wes had died. What they obviously hadn't done is tell the young guy who came out to pick it up. So when he came out he just said, "Well where is he?" And so I had to tell him, and he was really shocked and gutted, and it was particularly hard because, which was our last holiday so it was sort of a few months before, the wheelchair had actually broken down while we were on holiday, which had never happened before, got stuck in Barnstaple and it wouldn't move, get us in or out of the car, not the car this time, it was the wheelchair. So we had to break our holiday short and come home from Barnstaple, give a request to the chair mechanics, then they had the wrong parts and came out with the wrong parts, so Wes really was very angry with this young man, which was unfortunate 'cause he wouldn't normally have done that but it was just a bit much, you know, "I've come all this way and I still can't get the part!" And then the young guy had had to go away and then come back with the other one. So unfortunately his last thing hadn't been particularly positive either, and it's those things that were a shame really. But still the fact that they sort of cared in their way of doing things. And there've been endless people both, I mean the Invacar's, Wes would build relationships with the car mechanics, the engineers, 'cause he was always so interested in what went on. So whenever you'd have a phone call here he'd always go into a lot more detail than anybody else, and if we went to garages we were then as long talking with him about the engineering aspects of the car than anything else. But it was that relational building, and so Wes was always known as Wes, and a lot of people say they forgot the wheelchair and things because Wes didn't really give you time to think much about that, and work its way through. So I mean in and out of the borough of Kingston we never really tried public transport much at all until we got involved in doing a piece of research, I think it was for London Transport, this must be about five years ago, and we were given a day and sort of all those tickets. We could go round, we had to clock what we were doing where and when, and we managed to get ourselves out, we did the K2s into Kingston and we then went to Richmond and we got ourselves out at the top of Richmond Hill and had a little drink at one of the pub's, 'cause we were on the bus so it didn't matter! [Laughs] And then came back via different bus routes from there and clocked that out. And actually that did start him using the buses a bit more, and because he then had some appointments at Kingston Hospital and the parking used to be dire for cars, in fact at times he would then tend to go on the bus to Kingston Hospital. But he has some stories of that as well, of times, and including once when we were really dressed up for an evening do, which we didn't do very often, in Kingston, and we went up and the ramp got down to get us off but then didn't go back up on the bus, and we stopped and watched and we felt awful then for all the people on the bus because we'd sort of caused it and they were stuck, although we'd got to where we want, and it's those sorts of things. I mean he had quite a lot of experiences of not being able to get on when the buses were full and the buses going past because they were full. And then literally about three weeks before he died he took a photo of a bus, he was trying to get on outside Kingston Hospital and there were road works in Galsworthy Road, and a van had parked by the bus stop so the bus couldn't park where it needed to park to put the ramp down to get him on. So he actually took a photo of the van and then said, well he'd wait for the next bus or wait until that guy had gone, and he tried talking to the guy who came back to do the van and got sworn at, so [laughs] he wasn't too enamoured with that. So it's those sort of dilemmas as we try and get better on things. But he did more at going on the buses in his last few years of life. Trains, I mean our local Berrylands station, don't stand an earthly because there's steps everywhere. Surbiton now have got ramps so we could push or just about do an electric--, well no, we didn't do the electric chair at Surbiton. So if we went on the train I pushed the small wheelchair. And then there are the lifts now at Surbiton, but we've learnt again you need to ring beforehand to check they're working 'cause if they aren't you don't stand a chance. So we have done London a couple of times on the train. It's sort of reasonable but again it's waiting for ramps and knowing where to go to let people know that you want the ramps for where. But otherwise we would usually tend to drive up and then help by the fact that he's not under congestion charge with the disabled chair, so we could do that. And we got to know where there were key disabled parking spaces, sort of around for the theatres and things if we wanted to do those. So we used to tend to really drive up for those, and being musical actually, the Albert Hall was our main one and there was always, usually we'd ring and we'd get parking somewhere then and helped in. So it was--, but again then you begin to get to know people and a lot of it was the relationship building that made things work probably best.

Q: Was he involved with--, you say about the research for Transport for London, was he involved with other campaigns within the borough?

A: He went with Ed Davey to something, there's a picture of him with Ed Davey, I can't remember what they were particularly talking about at that point, and he then actually with Ed Davey's link, he became very involved really with the Lib Dems, which were just round the corner. So he used to go round there and do all their envelopes and stuff envelopes, and then become a teller at the things with them. So he became quite involved but I mean I think that was Ed, well Ed Davey and then neighbour Malcolm Self is a councillor, and so those links, so again it's local and relationships got him very involved really with Lib Dem and then, I mean whether it's--, I think he would have been there whether he was in a wheelchair or not actually on a lot of things there, but then he did become a representative for that. So he went up to the House of Commons with Ed Davey for something at one point, and then he used to go to the AGMs for KCIL and sort of see what was going on. There were varying things about ramps because at that point he was Barclays bank in Kingston when Barclays didn't have a ramp, and so he then, I don't know whether he actually wrote something in the end for somewhere, because he held out, he was given the option of, he could go to HSBC or one of the others that did have a ramp and do his money, but he said, no, he'd either go to Surbiton at that point, which he could get into, or he would just wait outside for a nice person to come and go and tell somebody and then they would come out. So again he would stick out sometimes for things. He wasn't somebody who felt he should have everything actually. He was grateful for what was there. He became very aware of the challenges of getting some of these things happening, so there were times he wouldn't have pushed for things that he felt, almost with his engineer hat on, that's not just going to happen overnight. You know, you can put things there but you can't expect certain things, and he could be quite hard at times of thinking, you know, we shouldn't necessarily ask for everything as we want it. We can sort of make little steps but we can also work on things ourselves. So he was a creator of gadgets, I mean we've got gadgets to hold bottles here and to sort of adapt his wheelchairs to things. So much to the frustration of some of the engineers of the wheelchairs [laughs], so he could make little things, but they were personal things then that made things work. And were there other things he'd have--, he'd get cross at times but it was trying to find, he'd try and find ways to do the best he could with things I think, within a borough. I mean he managed flights, we were fairly loyal to British Airways [laughs], after the weekend they've had just now. But at times the things that would make him cross were if he said something and then occasionally you get the patronising perhaps responses where they don't think he knows what he's talking about. So they would override his choice and it would end up not right. I mean we had those moments sometimes where we'd sort of particularly selected a seat on the plane and then we were told, no, no, no, you don't want that one, you want something else, only to find that the poor people who have to carry him down the flight then have to go--, he'd say, "I told you!" And it's, at times when, I mean because largely he was used to being in discussion with people and creating things with other people, perhaps he wasn't always so good at being, when he was being told to do things and he wasn't listened to and then things went wrong, that's what would really frustrate him I think. And I suppose anything like that over equipment, over medication, over other things, if he felt he knew, which he did know his body really better than anybody else, and then he was overridden on it, then that's probably when he was at his most frustrated with stuff. But other we weren't perfectionists, you can't get through by being perfectionists, you make the best of what you've got and we did work as a team really.

Q: What financial support did you receive to ensure that he could live independently and that you both did?

A: Yeah, well it was really interesting actually because, I mean I found that quite difficult because I obviously, I fell in love with Wes when he was in his wheelchair anyway so to me it was Wes that I was marrying and okay, I mean I was trained, nursing trained by then, I was aware I couldn't keep on nursing because my nursing was then now going to be Wes, so I couldn't do nights, I couldn't do the other things. So I then trained as a health visitor, which was at least normal hours and then I could still get Wes up and put him to bed. So I saw those initial care things as part of our married life, so it was quite a long time before we actually signed the form for what was then the disabled allowance, DDA thing. And I struggled with that and I still struggle a little bit over this, what is care and what is care that I as a wife can carry out,

and what is paid care? And I think we need another term for care, I was thinking this, this morning, because aspects aren't nursing, and otherwise. So the term personal assistant that's coming in I think is more suitable, but obviously that wasn't on offer at that time. So we then had DDA on the half rating because really once I got Wes to sleep I wasn't having to get up in the night. So we went through on DDA. Wes was then working, I was working for a time and then I was off with Stephen and then played around, so it was mainly that DDA that took us through the bulk of it. Then, and we were, I say, you call it fortunate but we were fortunate on the way of the house. Because he had the accident claim, the accident claim bought the house, so the house at a time when you had something like for £23,000, sounds daft, you know, and everything's just [makes puffing sound]. So I mean those things we were very fortunate really and that wouldn't have happened now in the same way. So we had property so we haven't had the mortgage to worry about. We then had DDA and then we had salary, our own salaries. We then had the bulk of the equipment and the Invacar were provided. The medical equipment's always been provided, so all the urinary stuff and supplies have been done, all the pads for the bed, all the ripple mattresses, they all were provided, I mean I didn't talk about those. I mean those are the other things that I forget about because they become so much part of life. You get the box deliveries periodically and the same with all--, there were changes in the ways you'd get your supplies of all the incontinence stuff, and initially I mean we had so many different numbers as to who delivered what. And I think the other thing that used to frustrate us with those, I'm deviating a bit sometimes, was that there was always the assumption that somebody would be in to collect when they were delivering. And of course Wes was working and I was working or out, and that always took a bit of explanation. And so we went through a stage probably when we were in our thirties and forties of getting a bit cross about that. "No we're not in, we're actually out!" You know, and, but this expectation that, well you're disabled and so we can come and repair your wheelchair because you can't go anywhere else and whatever. But financially we--, so then as DDA, it was really only, what was it? The last about 15 to 20 years when those things have changed then, and he went through then all that discussion about payments, going through those changes. Then there were discussions over the costs of carers and that was where again you ran into slight problems because we were then given an allowance for a carer for so many nights a week, so they'd come out and talk to us and then I could have so many nights a year, most of which I didn't take, but they were there if we wanted, which was fine when you had, we had somebody like Jane who you could work through. Once it began to be these people that you didn't know who were coming and it never worked, then in the end if I'm honest, we didn't really want them, well because it made, almost caused more trouble than it was worth. So I certainly didn't go away for days and it was only work that I would then use them for. So there were those sort of dilemmas. Otherwise did we-, the car mobility for the first car, and then yeah, there was mobility, there was a sort of mobility with the Invacar, so you know, you weren't taxed for those working the way through, so you got all the car taxes and things done and blue badge of course then for parking. So it's all those things that actually do reduce your costs, things from there. I think those were the main aspects.

Q: Were KCIL sort of supporting any of the financial support or was it--,

A: No, no.

Q: More that he was involved from like an advisory point?

A: Yes, yeah.

Q: Yeah, okay.

A: Yes, yes, he was in, because there hadn't been anything particularly like that before, he sort of came in then yeah, kind of, see what's going on and what's happening and [laughs] put his voice in. I mean I never went to--, he used to laugh because he'd say, "We got lunch, we got lunch today!" And the varying bits there [laughs], or whatever. But I mean he worked as an electronics engineer then went self employed when that firm closed down. But then actually the other support he did have then, when the contract for the self employment stopped he did, actually the other help he did get was to go--, so he was in his sixties then, he did go to Job Centre with help, that was funding I think, and he then was funded on a course,

which he loved, doing a computer course down here, Kingston Adult Education, and he really enjoyed that. But again, built relationships with everybody down there [laughs] so that then even if he had trouble later on he could still go down and talk to them about it. And then he got a job, which was through somebody at the Job Centre that had made that link, with a company that he could work at home for, and that was all these phone conversations that come through to private homes and things about--, and they say your phone call may be monitored for business, he was working for a company who were doing the monitoring of some of those calls. So he learnt how to do all that, he had big Excel spreadsheets and stuff he'd work through on the computer, and he was doing that right up until the last, I've just been doing his tax forms, right up until sort of six months or so before he died. The work started to tail off and so he did his last one about sort of six months before. So really I mean he was working right up until 70 doing different bits and pieces with his own income, keeping himself just sort of busy with bits and pieces really.

Q: How old was he when he passed away?

A: 70, 70 and, well he was 70 in the July and he died in the September, so almost 70 and a half.

Q: And that was 2015.

A: Yeah, December 2015, and by that time we'd been married 41 years, so we hit our 41<sup>st</sup> wedding anniversary but not our 42<sup>nd</sup> from there, so it's hard.

Q: Yeah. In terms of sort of challenges that you saw, particularly in recent times of changes that are being made to the provisions and services available, was there anything in particular that really stood out that you really noticed a shift in what was being offered?

A: Doing this talk, to me it's relationships again, because so much can be sorted out if you have somebody that knows you that you don't have to keep repeating the same things time after time after time, and who also has a holistic awareness. Because what was beginning to happen here was that we were being--, so was under Surrey county for urology, he was under St George's for neurology when they were looking at that, but then he also, he had a carpal tunnel actually, this was when the arm that had done really all the work was really wearing and tearing, and so that was back under Kingston, which one funny really, go in for a day job for carpal tunnel and obviously the house doctor or the registrar, he noted, signed out the piece of paper to say he could go home and on the paper it says fully mobile and he ticked yes. So I said, "How is it that magically at 68 you're now fully mobile?" [Laughs] I mean we did have to laugh about that one, you know, but it's about how people aren't seeing, they're seeing, okay, he's fully mobile as far as the arm is concerned, you can go, you know. Well we could have done a bit more on that but we had a laugh. And then it was Queen Mary's Roehampton for the cushions and the wheelchairs and everything else. Then there were the private wheelchairs, and then one social worker that would deal with one thing until this last really good one who then started to try and pull everything together, and different people trying to, again with accounts, I mean we had several visits from, again it was somebody via KCIL I think then that would fill in forms and then we'd wait for messages. And then I had to go, I had to be interviewed by somebody, and then it would be somebody different, and then that person would have left so then somebody else would come back. And so that was over, that would have been about 2013, 2014 to 2015 time, where these changes were coming in and I think different people were trying to manage them but there seemed inconsistency in messages that we were getting as to what we could do and what we couldn't do that you just began to be a bit confused. And then, 'cause from the, because we tied between the social care side, as they called it, and the nursing side, there were differentials there. Now, when I was nursing and we had the first community nurses in they would have lifted Wes on and off beds and in and out of the toilet and all that, but that would have been one person could have done the whole lot. Now, aspects of the toileting are within the community, the social care side, the nurses will come and do the catheter, and this was exactly the challenge we had over that last time. But they are funded by different people, their rotas are operated by different people, they're short staffed, they're all running under pressure, they have timed minutes as to how long they can stay with you, there's nothing to say that there's any connection between those two and it's no fault of any of theirs that that is difficult. In the same

way for the community nurses, they can't carry perhaps as much equipment as they used to, so if they haven't got the right catheter in then they've got to go back, they've got to find it, they've got to get somebody else to order it through. Or in the end we could keep so much here but then we had different contracts with different people for catheters as we did to bags and so on. So they were all, everything got broken up and that, a, it lends itself to confusion, it lends itself to far more phone numbers on here, far more mixed messages, and I think far more, far less job satisfaction. So you see people leaving jobs quite quickly too, and that was sad, and that to me--, and I mean that includes to some extent the way the health centres operate now where you're never quite sure who you get. I mean I'm beginning to learn the way that you book, you now do online booking and you try and get a time when the person that you really want to speak to is there. But you have to learn to play those systems and I think for the last few years of Wes' life these systems were in the process of so much change so quickly that they're not really settled, and when you have people who are absolutely dependent on routine and regularity that they're thrown. If they're thrown you get increased problems, urinary infections, pressure sores that will come up. Whereas if that routine is done consistently we're preventive medicine. So the preventive side of it seems to have been put on the end and we seem to now work with purely reactive, where we're dealing with the problems but we haven't got perhaps always sufficient people in the right space with sufficient expertise at the right time to run it, so, good [laughs].

Q: Frustrating. I think that's all of my questions but was there anything that I've not asked you about that you wanted to talk about?

A: I think for this I've separated or tried to separate out different aspects of care. I think I really have to put it in context that normally I wouldn't do that, and so the bulk of our life for 41 plus years of married life has been about husband, wife, father, son, grandfather, active members of communities with neighbours, church community, family. And then let's say that the real, the way that we have valued the support systems from, in everything, the NHS, the social care and all that support system that enabled Wes to have that ability to live, and that's what he did. And it is seeing, he was Wes right the way through as most of the doctors and nurses and carers will say that have come into contact with him, I'm sure, he was able to be his unique self in all of this, living in, we now call ourselves Berrylands here when it used to be Tolworth and Surbiton, so, but within this community, and that he's actually been able to live, at one point he was given a life expectancy of 25 years in a wheelchair from Stoke Mandeville, which he far outlived. So he hit over 50 years in the end from 21 to almost 71 in a wheelchair. One other bit of research he did do was with Stoke Mandeville Hospital on being some of the perhaps longer survivors of paraplegia from there, but obviously he's out of that one there. So he's been through changing times from the start of the growth in Stoke Mandeville and the support and everything else really and working it through. And he's had a great life and it's been a privilege to have been married to him for 41 years, and be mum of his son and one grandson and another one about on that way.

Q: How exciting, congratulations!

A: Thank you.

Q: Lovely, well then I will end it on that note, thank you very much.

**[END OF RECORDING – 1:05:47]**